

Arkansas

Spinal Courier

A Publication of the Arkansas State Spinal Cord Commission

September, 1989

Arkansas Spinal Cord Disabled Play Key Role in Research Project

Disabled Arkansans are being asked to play a key role in a new research grant awarded to the Arkansas State Spinal Cord Commission by the national Centers for Disease Control.

The purpose of the grant is:

- To create a nation-wide standard for the reporting of spinal cord injuries.
- To increase the amount of information kept on file for each spinal cord client in Arkansas.
- To expand and evaluate current Arkansas spinal cord injury prevention projects and plan additional prevention strategies.

According to Cheryl Vines, Executive Director of the Commission, Arkansas was

selected over 13 competing states because of the quality of the information available here. "Arkansas has some of the best data on spinal cord injuries in the country, said Vines. We are the only state in the country with full-time case managers working directly with the spi-

nal cord disabled. This allows us to closely monitor client service needs and as a result maintain an accurate base of information about the spinal cord disabled."

Although an information file already exists for each client, the research project will require the collection and analysis of additional information not presently maintained by the Commission. Disabled Arkansans are being asked to provide this additional information through interviews, questionnaires and phone calls with the research project and case manager staff. According to Tom Farley, Director of Research and Statistics, data

collection began on June 26, 1989 and will be completed by February 2, 1990.

By studying exactly how and under what circumstances Arkansans

were injured, the Centers for Disease Control can design an effective nationwide campaign to prevent spinal cord injuries. Thus, by telling their injury story, Arkansans will help prevent others from becoming injured in the future.



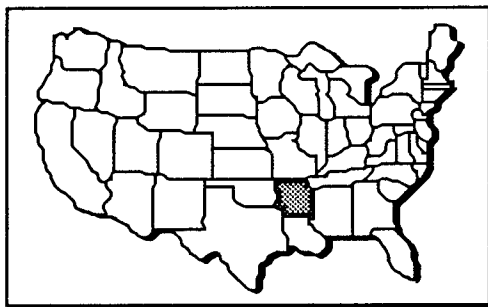
**Vines New ASSCC
Executive Director**

Cheryl L. Vines began her duties as Executive Director of the Arkansas State Spinal Cord Commission on April 24, 1989.

Ms. Vines brings a wealth of experience and enthusiasm to her new position. Be sure to read her HELLO! letter on page 2 of this issue.

Bill Duff Wheels Across America!

Bill Duff, wheelchair athlete from Houston, Texas has completed his Wheels Across America Tour. Bill left Los Angeles, California on January 17, 1989 pushing 50 miles each day. He passed through Arkansas in early April. Reaching his destination right on schedule, arriving in New York City on July 28, 1989, Bill had covered 5,000 miles. Wheels Across America was a promotional tour to raise funds for the Miami Project to cure paralysis.



Arkansas *Spinal Courier*

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Thomas L. Farley
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BUCKLE UP!

Safety Tips For Transporting Babies and Young Children with Special Needs

Arkansas Act 749 of 1983 requires that child safety seats be utilized when transporting children under age three in passenger cars. Children between age three and five can be transported with a safety seat or a seat belt. The child restraint law is necessary because motor vehicle accidents are the major cause of death and injury to young children.

Parents of children with special needs such as low birth weight, orthopedic, neuromuscular and respiratory problems have great difficulty using conventional restraints.

These parents have an even tougher time finding adaptive child safety seats that have been certified to meet all the requirements of Federal Motor Vehicle Safety Standards.

Fortunately, test data has proven that many children with special needs who are under 40 lbs. and 40 inches in height can get the support and protection they need by using standard child safety seats. The standard seats are also lower in cost than adaptive restraints and easier to install and use. The American Academy of Pediatrics (AAP) offers the following tips for "special need" parents who prefer to use standard child safety seats:

- Do not alter a child safety seat (CSS) unless the modification has been crash-tested.
- Use CSS's with a 5-point harness, which can be adjusted to provide good upper torso support.
- If an infant's head falls forward, tilt the CSS so the child reclines at a 45 degree angle.
- For children over 20 lbs. with poor head control, use a convertible seat that can be semi-reclined facing forward.
- Cloth rolls can be used for lateral support of the child's trunk and head, between the legs and the crotch strap to reduce slouching, or undo the knees in front of the crotch strap to reduce arching.
- If padding is needed behind the back, use a folded cloth, never a soft cushion.

• Do not restrain the child's head separately from the torso.

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HELLO!

We are pleased and excited to bring you this first issue of the Spinal Courier, a bimonthly newsletter designed to serve as an information and communication network for people with spinal cord injuries and their health care and other service providers. We look forward to utilizing it to answer questions and disseminate information related to spinal cord injury including resources, research, equipment, medical problems and recreation. If you have information you'd like to share or questions you'd like answered, let us hear from you! If you learn just one thing new each issue, we've met our goal!

As you may know, I assumed the position of Executive Director in April. I bring to the Commission my 13 years of experience working with Spinal Cord Injured people in rehabilitation and community settings as well as my enthusiasm for the many new projects and plans that we are undertaking! This issue covers our Surveillance Project and as other plans are finalized, you will be learning about them through your case manager and this newsletter. I look forward to meeting and getting to know more of you. If you have a comment or a concern about the Commission or our services, please let me know!

Last month, I watched in the media with interest, Mark Wellman (a paraplegic forest ranger) as he climbed El Capitan, a 3,200 foot granite cliff in Yosemite National Park in California. I was struck once again by just what a person CAN DO when they choose to! It was Mark's ABILITY that took him up the face of the mountain, 6 inches at a time. We all have our own El Capitan, a challenge or goal that we want to accomplish and with planning, determination and perseverance (and sometimes a little help from a friend) almost anything is possible! Find your El Capitan and GO FOR IT!

Cheryl L. Vines
Executive Director

ARKANSAN GOES INTERNATIONAL

The Arkansas flag flew over England in July, because Jonesboro's Grover Evans never leaves Arkansas without one. Evans, a C-6 quadriplegic met a personal goal this summer, when he was selected as a member of the U.S. Team attending the annual Stoke Mandeville Wheelchair Games in Aylesbury, Bucks. The only Arkansan on the team, Evans was one of three U.S. competitors in the Table Tennis Competition, bringing home a 4th place finish in his IB classification. Grover had qualified during National Competition in Miami this spring, where he assumed a national ranking of 647 in U.S. Table Tennis (standup and wheelchair).

Involved in wheelchair sports since 1982, Evans has competed in numerous sports; including swimming and track and also holds triathlon records in his classification (3/4 mile kayak, 5K wheelchair push and 400 meter swimming) 1 hour, 43 minutes.

Also active in his community, particularly as a Jonesboro alderman, Evans attributes much of his personal psychological and physical health to participation in sports and takes that message out in his many opportunities to speak to groups: "Regardless of my physical capabilities, I am an athlete first. Just like those who walk, I am a true athlete."

What's next? Grover has an eye on a spot on the U.S. team slated to compete in the Pan American Wheelchair Games in Venezuela in 1990 and then, the 1992 Paralympics in Barcelona, Spain. "You cannot describe the feeling", he states, "of representing your country in international competition, there's just nothing that compares to it."

Grover also issues a challenge to anyone to try to beat him at table tennis! Any takers?

MEDICAL DIRECTOR'S REPORT

by

Shirley McCluer, M.D.

One of the most important reasons why a Spinal Cord Commission was created in 1975 is the number of severe, costly medical complications that can occur in individuals who have damage to the spinal cord. Many of these complications are so specialized that the average well trained physician is not familiar with how to recognize or manage the problem. For this reason it is essential for each spinal injured individual (and concerned family members) to become as well informed as possible about these medical complications and to participate actively in their medical care.

To achieve this you should:

1. Read and learn as much as you can about all aspects of your condition. Ask your doctor or case manager for suggestions.
2. Do not hesitate to ask your physician to explain to you any tests that are done, the reasons for any medications, possible side effects to watch for, etc.
3. Don't be afraid to question what your doctor says. Remember, it is your body and your life and you have a right to share in medical decisions.
4. If you have doubts about what is recommended, request a second opinion from another physician. No reputable physician should resent such a request.
5. When possible, try to locate a physician who has had experience with spinal cord injuries. If that is not possible, find a physician who is willing to listen to you and learn. Give the doctor any reading material you have that may be helpful in your management.

In future issues, of the *Spinal Courier*, specific medical problems will be discussed. If you have questions that you would like to have answered, please write to Medical Director in care of this newsletter.

Safety Tips

Continued from page 2.

The AAP also offers the following tips for transporting children in wheelchairs:

- Wheelchair passengers should ride facing forward.
- Anchor the wheelchair to the vehicle with a four-point tie-down system that has been dynamically tested.
- Secure the occupant in the wheelchair with a dynamically tested restraint system which includes a shoulder harness for upper body protection as well as a

lap belt.

- Use all tie downs and occupant restraints according to manufacturer's instructions.

For more information concerning additional adaptive devices or for transportation support for children with special needs once they outgrow the child safety seat contact:

Safe Ride News
American Academy of Pediatrics
P. O. Box 927
Elk Grove Village, IL 60009-0927

Resources

Employment After Spinal Cord Injury: A Handbook For Counselors by Nancy M. Crewe, University of Minnesota, Minneapolis, 1978. The first section describes employment problems and solutions, the second section consists of 79 short biographies of working wheelers, with an emphasis on quads, and the last section is an index of professions suitable for the severely disabled.

Housing And Home Services for the Disabled, by Gini Laurie, Harper and Row, Hagerstown, MD. Everything you need to know about architectural adaption, attendant care, residential options and government assisted projects.

The Accessible Home; Renovating for your Disabled Child by Heather Snell; Is Five Press, 467 Richmond Street East, Toronto, Canada M5A 1R1; 1983 cost \$9.95.

How to Fill Your Toy Shelves Without Emptying Your Pocketbook: 70 Inexpensive Things To Do or Make, Available from the Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091; cost: \$3.95. Designed for parents and teachers, the manual contains suggestions for approximately 70 inexpensively constructed games, activities, and manipulative materials for use with handicapped and non-handicapped children.

Toys For Special Children includes over 100 items which have been specially designed for children with minimal movement. Includes toys, activity centers, training aids, communication devices and switches. Cost \$3.00. Can be obtained by writing Steven Kanor, Ph.D. Inc., 8 Main Street, Hastings-on-Hudson, New York, NY 10706.

The Clothing Research and Development Foundation, Inc.
One Rockefeller Plaza, Suite 1912, New York, New York 10020
Offers catalogs of clothing and aids for persons with disabilities and general information on functionally designed clothing.

Arkansas Spinal Courier

Arkansas State Spinal Cord Commission
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National Spinal Cord Injury Association Chapter Formed in Central Arkansas

Efforts have been underway during the past few months to establish a chapter of the National Spinal Cord Injury Association in Central Arkansas. In a March organizational meeting, it was decided that Pulaski, Saline, Grant, Lonoke, White, Conway, Faulkner, Perry, Garland, Hot Spring, Jefferson and Pope counties would make up the membership area. The group next met in April and began work on by-laws. Other planning meetings are being scheduled and announcements will be forthcoming. If you or someone you know is interested in helping establish this organization, please call Gene Hamilton at 371-1804 for further information.

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